Ashley's story

Sunday, August 27, 2006 I went to Marsh, as usual, and purchased a bag of Dole spinach, like I always did. We had it for dinner that night as a raw salad with our spaghetti and meatballs. Both Isabella, my 5 year old, and Ashley, who was 2, and I had the spinach. We always worked very hard to make sure our girls ate healthy. This generally meant lots of fruits and vegetables and very little sugar.

By Saturday, September 2, 2006, Isabella had come down with Colitis from the spinach. Of course at this point, we just thought she had a viral diarrhea. She had the diarrhea for almost a week when I finally took her to the doctor. It was on Friday, Sept 8, 2006, and the doctor just said that it was a viral diarrhea and there was nothing that she could do about it. She just said to keep her hydrated, and to let the doctor know if she had blood in her stool.

Isabella started feeling better the next day, and we thought we were in the clear. Then, about mid-day on Saturday, September, 9 Ashley started having diarrhea. We just thought she caught the same bug that Isa did, and just kept giving her fluids and keeping an eye on her. She was pretty lethargic that day. She would drink fluids, but was not really interested in food (which is a shocker for anyone who knew her!!). The next day, Sunday, she seemed to feel a little bit more like herself. She ate a little more, and she was more interested in playing. We even went to my sister's wedding shower, where she played with all of her cousins and seemed to us like she had got the bug out of her system. By Monday, however, she was feeling much worse. She was very lethargic, slept a lot and did not want anything to eat and very little to drink. She still had diarrhea. We went out and got haircuts for the girls that afternoon, but she definitely was not feeling like herself. At this point she was more lethargic again and wasn't interesting in playing.

By Tuesday, September 12, 2006, she was getting worse and I knew something was really wrong. During one of the nearly a dozen diaper changes in a day we were doing at this point, I noticed she had some blood in her stool. I remembered what Isa's doctor had told me and I called and scheduled a sick appointment for Ashley that day. We met with the doctor and she still felt that it was viral diarrhea and nothing to worry about, but because I had brought the diaper with me, they tested it to see if it was in fact blood. The

doctor felt that Ashley looked dehydrated and wanted me to go to their other office in Castleton to get a blood draw to find out for sure. I took Ashley to the other office, where the nurse there drew her blood samples and sent them to the lab for analysis. I then took Ashley back home to wait for the results.

About an hour later I got a call from my doctor telling me that Ashley was in fact dehydrated and wanted me to take her to Community North hospital. They told me not to worry, that they would just admit her to get an IV in her and they would monitor her hydration levels and we would probably be out of there that same night. So, on Tuesday, September 12, 2006, we checked into Community North and they hooked her up to an IV to re-hydrate her.
Right after checking in and getting her into her room, the nurses had to come in and hook up the IV and all of the wires to monitor her with. Also, because of the diarrhea in her diapers, the nurses could not tell if she was producing any urine so they inserted a catheter into Ashley to monitor this, as well. So, always having been a healthy baby, this was Ashley's first introduction to the world of pain and needles. She was such a trooper, but how sad to be grateful that God had blessed you with a cooperative child. How sad that at the tender age of 2, Ashley was about to learn that she just had to become resigned to being poked, prodded and generally tortured to get her better. She always had been a good, healthy eater and was plump with health. Seeing her lying in that hospital bed, she was so unnaturally skinny and sickly, it was so sad.

It is now late afternoon on Tuesday and Ashley is still having countless diapers with diarrhea, not producing any urine, and now she has started vomiting. At first the vomiting was bile, yellow in color. But as the night progressed and it got into Wednesday, the vomiting started to get darker and darker green. Our Dr did stop by later that afternoon to see how she was responding. I asked her what else we should be doing because this did not seem to be helping. I also asked her if she had tested for e Coli. I remember she looked at me strangely for asking, and I don't remember now exactly what she said, but I think the answer was yes.

By Wednesday, September 13, 2006, the vomit was almost black, she could barely even sit up by herself, she still was having diarrhea, and that was when I had finally had enough. The IV was not making her better, her vomiting was getting worse, she was not producing any urine, and to me she looked like she was getting puffy. I had not seen my doctor since yesterday and I grabbed a nurse and told her to call her immediately. I told the nurse all of these things and told her she needed to get my doctor in to see me, NOW. About 15 minutes later the nurse came back into the room and told me that my doctor had ordered that Ashley have some labs run on her. So, the nurses came in drew a few tubes of blood and sent them to the lab. I don't remember how long we waited, watching poor little Ashley cry and lie in her bed, but I remember how small and helpless I felt. We did not know why at the time, but Ashley was inconsolable. She did not want to be held or even looked at! This just broke our hearts, because as a parent, you always want to comfort and take away the pain of your baby, and also because this was so out of character for little Ash. She always wanted to be held, especially when she was sick. To see her screaming and banging around in the crib like a caged animal was more than we

could stand. When she was happy and healthy, people often asked us, “is she always like that,” referring to how smiley and friendly she seemed.

When the nurse came back to tell us about the lab results, I knew something was wrong. She came in and told us that our Doctor was conferring with someone at Riley and would call us as soon as she was done. The nurse did not offer any other explanation, but did say that our Dr would call shortly. When our Dr did call, I spoke with her first. I don’t remember all that she said, but I remember her asking if I was still there. I could not speak because I was choking back tears. She told me that Ashley’s blood tests showed that her kidneys were shutting down. This was why she was not producing urine and why she was getting puffy. Her pancreas was also not working properly, which was causing the vomiting. I remember her telling me that as she was talking with this specialist at Riley, she remembered me asking her about e Coli, and she brought that up with him. Apparently it was that question that made our situation crystal clear to what was happening to our baby. She mentioned something about HUS, but she said the specialist at Riley could explain it better once we got down there. I still do not know how our Dr got in touch with the person at Riley that she did, but I thank God for His hand in that today. The specialist she spoke with knew exactly what was causing Ashley’s kidneys to shut down. As our Dr tried to explain to us what was going on, my brain shut down. All I could think about was that she said “dialysis” and not knowing exactly what that meant at the time and how scary it sounded. It was also scary when she said that the Lifeline ambulance from Riley was en route to take Ashley down there and that our Dr was transferring our care over to this specialist.

I thank God that she knew enough to call Riley. I thank God that she got a hold of the specialist at Riley who knew about this rare disease. I thank God that He made me ask about e Coli. And I thank God that He made me take Ashley into our pediatrician’s office that day to ask about the blood in her stool.

It was Wednesday, September 13, 2006, at about 4:30 pm when the ambulance arrived at Community North to take Ashley down to Riley. Three paramedics came into the room with this special gurney just for children and began unhooking her from her hospital bed and transferring her to the gurney. She looked so small lying there. We were told that we could not ride in the ambulance with her, so we just had to stand there while they wheeled our baby away. She was very brave and went quietly with the strangers as they wheeled her into the ambulance and took the trip down to Riley.

We followed the ambulance in our car. It was a very quiet ride for my husband and I, each of us lost in our own thoughts. Each of us was trying to be brave and tried not breakdown as we worried about what was wrong with our baby. We did a lot of praying, that was for sure.

When we got to Riley, we went straight to the ER where Ashley was. They were transferring her from the gurney to her new bed. They had to hook up all of the monitors all over again in her new bed, and then they had to insert a new catheter. I had to hold my baby down while they shoved the plastic tubing into her bladder again. I could do

nothing to help relieve the pain and discomfort that they were causing. She just looked up at me and was probably wondering why her mommy was letting them hurt her like this.

At this time, Michael had to leave to go home because Isabella was at home with my mother. He could not wait any longer for the specialist, but I assured him that I would put Michael on speaker phone when the Dr did arrive.

The Renal doctor on call, the one who spoke with our pediatrician, came in to talk to us (me in person, and Michael on the phone) about what was going on with Ashley. This was the beginning of our education about HUS and all of its ramifications. He described how in a small percentage of children, e Coli can cause Hemolytic Uremic Syndrome (HUS). He described all of the various implications it can cause in the body, from the brain, pancreas, kidneys, liver, etc. He explained that HUS can cause swelling in the brain resulting in mood changes, which was what was causing Ashley to be so inconsolable and angry. HUS was also affecting Ashley's pancreas, which was causing the vomiting, and obviously her kidneys, which were shutting down. He explained everything that could happen, even death. The main problem with HUS, he said, was that there was nothing that doctors could do to prevent it or to treat it once a child had it. The only thing that we could do was watch what it affected and then treat the symptoms. So, for now, all we could do was wait and see if her kidneys continued to shut down, and if so, we would need to put her on dialysis.

After he left and gave us time to digest, my husband and I were just speechless. We were terrified and did not know if our daughter was going to make it through the night. We prayed, called relatives, and then I settled in for a sleepless night in ER, and Michael to spend a scary night at home with Isabella and all of her questions. (Unbeknownst to us, this was to be our first of many of such long nights.) One thing I remember vividly is Michael telling me that as he was putting Isabella to bed that night she asked him, "Daddy, is Ashley going to die?" He answered her with tears in his eyes that, "No, God is going to keep Ashley safe."

The next day, Thursday, September 14, it was decided that Ashley's kidneys were not improving and that we were going to need to put her on dialysis to keep her alive. The type of dialysis that they preferred for HUS kids was peritoneal dialysis, in which a catheter is inserted into the peritoneal cavity. She was taken in for surgery, where they implanted the catheter, as well as a central line for her IV and her blood draws. Surgery took an hour, and all we could do was pace the floor and hope that she would come out of anesthesia ok. We had never before had to deal with anything like this in our life.

They called us to recovery after her surgery and a parent should never have to see their child lying semiconscious in a hospital cage, I mean crib. We were told that Ashley would be transferred up to the PICU as soon as a bed opened up. We waited for 5 hours in recovery. Luckily, I guess, Ashley was so sick that she just slept through this whole ordeal. Michael and I were not so lucky. We had to stand by her bedside waiting.

They finally came in and announced that a room had opened up, so Ashley was wheeled into her new home-away-from-home; a tiny hospital room that could barely hold her hospital crib, a reclining chair for us to sleep in and all of her dialysis and medical machinery. It is hard to write all of the emotions and fears that we were feeling through all of this. It was just surreal.

When we first got to the PICU, because Ashley's problems stemmed from e Coli, she was in isolation. That meant that anyone coming in and out of her room had to put on a gown, mask, and gloves. For an entire week, we had to make sure that she and the rest of the hospital was safe from any possible e Coli contamination. Luckily, since we were living in the room with her, we did not have to wear the gloves, but all of our relatives did not get to have any skin on skin contact with Ash the first week. This was very tough on Grandparents who wanted to hold their little granddaughter's hand.

Another thing I remember vividly was that Ash was hooked up to so many wires, plus the IV, plus her dialysis line. I could not hold my child. I went for more than 2 weeks without being able to hold or comfort or rock my baby girl. This was the first time in the two years since we had her that I did not rock her to sleep. And then when I was able to pick her up, it was with all of those things attached to her and I could barely move away from her bed. But it was worth it just to be able to hold her and feel her little head rest on my shoulder.

The next 6 weeks were somewhat of a blur. It is hard to explain to someone who has never lived through something like this how time just seems to stop. In the first few days and weeks we watched Ashley go from being swollen with excess fluid, to too much fluid being removed and she looked like a skeleton. I remember how Michael would not even let me mention how skinny she looked and how sunken her eyes were because we were just so terrified of what that might mean. Our lives were consumed by nurses coming in every 2 hours to check vitals and draw tubes of blood. Every time Ashley would move in her crib, she would set off her monitor alarms, so we never got any sleep.

Ashley was on 24 hour dialysis while in the PICU. There was no doubt from any of our doctors that Ashley had HUS, but because there was nothing else to do but wait and see if her body got better, one of her specialists decided to run all of the blood tests he could think of to see if maybe he could find some other cause for her kidney failure. We think he wanted it to be something else that was treatable instead of just waiting and seeing. All of the tests came back negative. This was definitely HUS, and we would just have to see what would happen. They told us that most kids with HUS have their kidneys come back in a few weeks. They told us that they could not estimate when Ashley's would come back, but they did tell us that the longer she remained on dialysis, the more worried they became about permanent kidney failure. Again, nothing to do but watch and pray that her kidney function would return.

Our lives revolved around blood test results, and seeing how much, if any, urine she produced. We prayed for pee. Any tenth of an ounce was celebrated. It was maybe a month in before we even saw that much. But, finally, Ashley's kidneys did start to pick

back up again. They slowly weaned her off of 24 hour dialysis by going from 6 exchanges with 4 hour dwells, to 4 times a day, the fluid dwelling for 6 hours.

At some point Ashley's kidneys started picking up a little more to the point where she could be off of the dialysis machine, and she was put on to a manual form of dialysis. This was with a contraption called the "octopus" because this is exactly what it looked like. All of Ashley's dialysis bags for the day, or a few days, were placed on this huge IV pole, and she would then be manually filled and drained every 4 hours. This was another challenge we had to learn to deal with. The good part was that she was now "mobile". The bad part meant that if we wanted to take her for a wagon ride, we had to drag her IV pole and this dialysis pole along, too. This was not a one-man job. That meant that the only time Ash could go for a "walk" was when both of us were there to help. But this was still a blessing. For the first time in over a month, Ashley was able to get out of her hospital room. This was the highlight of her day and ours.

Finally we got to the point where her exchanges were stretching out longer and longer, we could take walks for longer periods of time. I remember the first day that we actually got to take her outside for the first time in over a month. When it just got too cold and we had to come back in, I remember how I thought her little heart would break having to go back into her hospital crib. A 2 year old should never have to be confined to a cage.

And have I mentioned all of the medications this poor little child had to endure? Because kidneys touch every function of the body, and because hers were not working, they were not doing a lot of their jobs correctly, like being able to clear potassium, or other critical jobs. So, Ash had to take terrible tasting medicines, and still does. We would have to hold her down while we squeezed this black ooze into her little mouth. I don't remember what that medicine was for, but it was awful. There will be more about current medications later.

When we got to the point where she could be on the 4 exchanges a day, they transferred us to the regular pediatric unit. At first we were excited about getting out of the PICU, and avoiding the every 2 hour check-ups by the nurses. We quickly learned how wonderful we had, in fact, had it. Going to the regular floor meant sharing a room. We had the horrifying experience of living in a Jerry Springer episode. Our roommate was an eight year old girl, who was actually very sweet. Unfortunately, she had a mother and a sister who were not so considerate.

Our girls have always gone to bed early, and then awoke very early. Ashley would go to bed about 6:30 or 7 pm, and then she would wake up about 6 am. Surprisingly we were even able to keep to a close proximity to this schedule in the hospital up until now. But now, we were living with extremely rude people who were not only awake until after 11:00 pm every night, but they also had countless visitors and were very loud. Poor little Ashley would finally just pass out at night because she was so exhausted. And of course, we never got any sleep because of them.

We lived through weeks of that hell. Finally another room opened up and we were able to move, but again, it was still a shared room, and their schedules were always different than ours.

Again, if you have never had a seriously ill child, it is hard to understand the strain that living in a hospital puts on you. You are, of course, worried sick about whether or not your child will make it through it all, let alone be normal again. But, there is also the strain of not getting any sleep. They do provide one chair that extends to be a "bed", but it is hard to sleep on it, especially when nurses come in every 2 hours, and her monitor alarms go off every hour or so. Then there is the minor detail of showers. I will say that Riley has the Ronald McDonald house, which was definitely a blessing. They had shower facilities that parents could use, so we did enjoy that.

And through all of this we had to balance the fact that we were also the parents of a 4 year old, who was not old enough to understand where her Mommy and Daddy were and why they had essentially abandoned her with her Grandparents. For the 2 months that we lived in the hospital, our 4 year old lived without us. We missed her so much, but the hospital was no place for her, plus she could not understand what was going on with her sister. We only got to see Isabella for a couple of hours each week. It was heartbreaking to have to say good bye to her each time she left again. I have it burned into my memory the sight of her staring out of the backseat window driving off with tears in her eyes. There is no way of knowing what affect all of this had on her. I do know that we are still dealing with the after effects of all of this. She still needs constant reassurance when we are leaving her that we will in fact be coming back. She is much clingier, and does not want us to leave her side.

Another aspect that we had to deal with was the fact that both Michael and I had full time jobs. There was no question that one of us would always be in the room with Ashley, so it was extremely difficult to balance it all. We had our computers with us, and we were able to work a little bit while Ashley was sleeping, but in the end both of our boss's had had enough. The biggest issue this has all had with respect to our careers, is that we are both relatively young and had plans to advance our careers. Now, this is not so easy.

When Ashley's dialysis got the point of 4 exchanges a day, her Doctor's felt comfortable with us going home. Michael and I went through several weeks of dialysis training at the hospital. We had to learn about care for the catheter exit site and how to give her shots several times a week (she requires shots of epogen because her kidneys do not properly control the production of new red blood cells). We also learned how to monitor her blood pressure.

But we were finally able to go home and get our family back together. Once at home, we were able to figure out our new schedule. Dialysis exchanges were done 3 times a day, blood pressure was checked twice a day, her daily medications were spaced out throughout the day and shots were on Monday, Wednesday and Friday. We also had to drive down to Riley every week for Renal Clinic. There we would have to have Ashley's blood drawn and see the dialysis nurses and the renal specialist.

Home dialysis came with several new worries. There was the constant fear of cleanliness and making sure our home was as germ free as possible, especially during exchanges. Then there was the new one of her blood pressure. Peritoneal dialysis uses fluid in the peritoneal cavity to filter out things that the kidneys normally would handle. A side effect of this is that the fluid can also be absorbed into the body. When there is too much fluid in the body, then blood pressure increases. We had one week where here bp spiked to 170 and we were right back at Riley for a weekend. That weekend we learned a lot about blood pressure and blood pressure medication. After that episode we spent a lot of time considering if Ashley seemed puffy and what dialysis solution we should use.

We were constantly struggling with maintaining her blood pressure with being on dialysis. We were also struggling with seeing a different renal specialist every week at clinic, depending on who was on call. We finally called Dr Andreoli, one of her specialists, and requested we meet with her specifically since she was the expert in this area. We told her of our frustrations with clinic and the lack of consistent care we were receiving because each doctor had a different idea of what we should do with Ashley's treatment. We discussed the problems we were having keeping Ashley's blood pressure in check with the dialysis. Dr Andreoli felt that maybe it was time to consider coming off of dialysis, since it seemed to be doing more harm than good with respect to her blood pressure. She said that we would just need to do more labs on Ashley every week as we started to wean her off to make sure her Creatinine could remain stable.

So, we began taking Ashley for blood draws twice a week to monitor her levels while we reduced the number of exchanges and then stopped them all together. (Let me tell you, trying to hold your child down while they stick a needle into her arm to draw out blood is an extremely painful task to ask of any parent and child.) So, even though her Creatinine levels are 3 times the normal limit for a child her age, Dr Andreoli said that did not need to remain on dialysis. She told us that the percentage of her kidneys that were working would learn to take over for the damaged parts. She told us that this would eventually wear her kidneys out and she will need a transplant, but she hopes that it won't be for many more years.

Ashley was on dialysis until the end of December. Even though she is off of dialysis, she will still be on medication the rest of her life. We also have to take her for blood draws every week to monitor her potassium and other levels. We have found that another side effect of kidney failure is a very strict dietary restriction of potassium, as well as other minerals. Her potassium levels are too high, so we have to monitor everything that she eats and drinks and she has to take a very disgusting, thick medication twice a day to remove the excess in her body since her kidneys cannot do it for her.
So, our once healthy eater is now on an extremely strict diet that she, and for fairness to her, all of us are now on. Because her kidneys are not functioning properly, we have to maintain an extremely strict, potassium-limited diet. And potassium is in everything, literally. We just have to find foods that have less potassium than others. So, bananas are out, period. Avocados and chocolate are out. (Remember, this is a 2 year old we are restricting this from). What else? All leafy greens, melons, potatoes of any kind, dairy,

yogurt, nuts, peanut butter, tomatoes and tomato sauce, and pizza to name a few. (Notice that most of these foods are a small child's favorites).

So every day, at the time this was written, Ashley takes 4 different medications orally everyday, and then we have to give her a shot every week. I am sorry, but parents should never have to hold down a 2 year old and force them to drink nasty, thick medications that make them gag and want to throw up. Nor should a parent ever have to hold a child down to stick a needle in their back side to deliver the necessary medications to make up for something their little body should just produce naturally. And as I mentioned before, we take her for blood draws every week, as well.

Ashley's condition seems stable now. The problem, and the constant cloud that is always over our heads, is that we don't know for how long. A kidney transplant WILL be required. That is a question of when, and not if. Michael and I spend a lot of time wondering how normal of a life Ashley will be able to lead.

IT is hard to put down in words all of the fears that go through our heads on a daily basis now. We worry about Ashley and her future. We worry about when her kidneys are going to stop working for good, and if she will ever be able to get married and have children of her own one day. Our doctor has told us that the stress of puberty and pregnancy are serious concerns for Ashley.

We worry about if she will grow normally. Because her kidneys do not function properly, her growth will always be an issue. We worry about numerous other complications and conditions that are brought about by renal failure. For instance, her PTH levels have been off lately, which is a measure that her Parathyroid gland not working correctly. Her carbon dioxide levels have also been off, which means that something with the lungs "talking" to the kidneys aren't working right either. The kidneys touch every part of the body, so we now have constant fear and worry in our lives that we never expected to have.

We worry about what life is going to be like as she grows up and goes to school. We will always have to pack her a lunch now because she cannot eat most normal school foods. How is she going to feel while all of her other friends are eating pizza, and she just has to sit back and watch. We worry about how she will ever be able to play such sports as basketball, or even softball, because can we really afford for her to get hit and possibly damage one of her kidneys?

We were a family that enjoyed cooking and eating new foods. We like to try new flavors and dishes. That part of our lives is over. Ashley just cannot have most foods. We also like to travel and had planned to take the girls to many places. We wanted them to experience other cultures. At this point, I don't see that kind of travel happening.

Like we mentioned earlier, our careers have no been put on hold. Michael had begun a serious search that should have resulted in a big career move. This effort has had to be put on hold indefinitely. Michael and I will always have to weigh the pros and cons of

moving jobs due to Ashley's now pre-existing medical conditions and that effect it will have on our insurance policies. We will always have to weigh job location and whether or not we will be able to have a renal specialist in the area. All career advancement plans have been put on hold.

We also talk about how we can try and get our lives back on track. A baby sitter for a night is not a luxury we are really able to enjoy. We are hopeful that this will be possible in the future, but her medications and general condition make this difficult. We cannot just use a neighborhood babysitter, because of Ashley's specialized care she now requires. Vacations are now are harder because we cannot be too far away from home in case something should happen while we are gone.

The only thing that we can do is focus on living day to day. Unfortunately, giving multiple medications and shots, and worrying about results of Ashley's blood tests are just a part of life now. We are hopeful that medical research will make things better in her future. We just pray that Ashley's kidneys can hold out for a few more years…